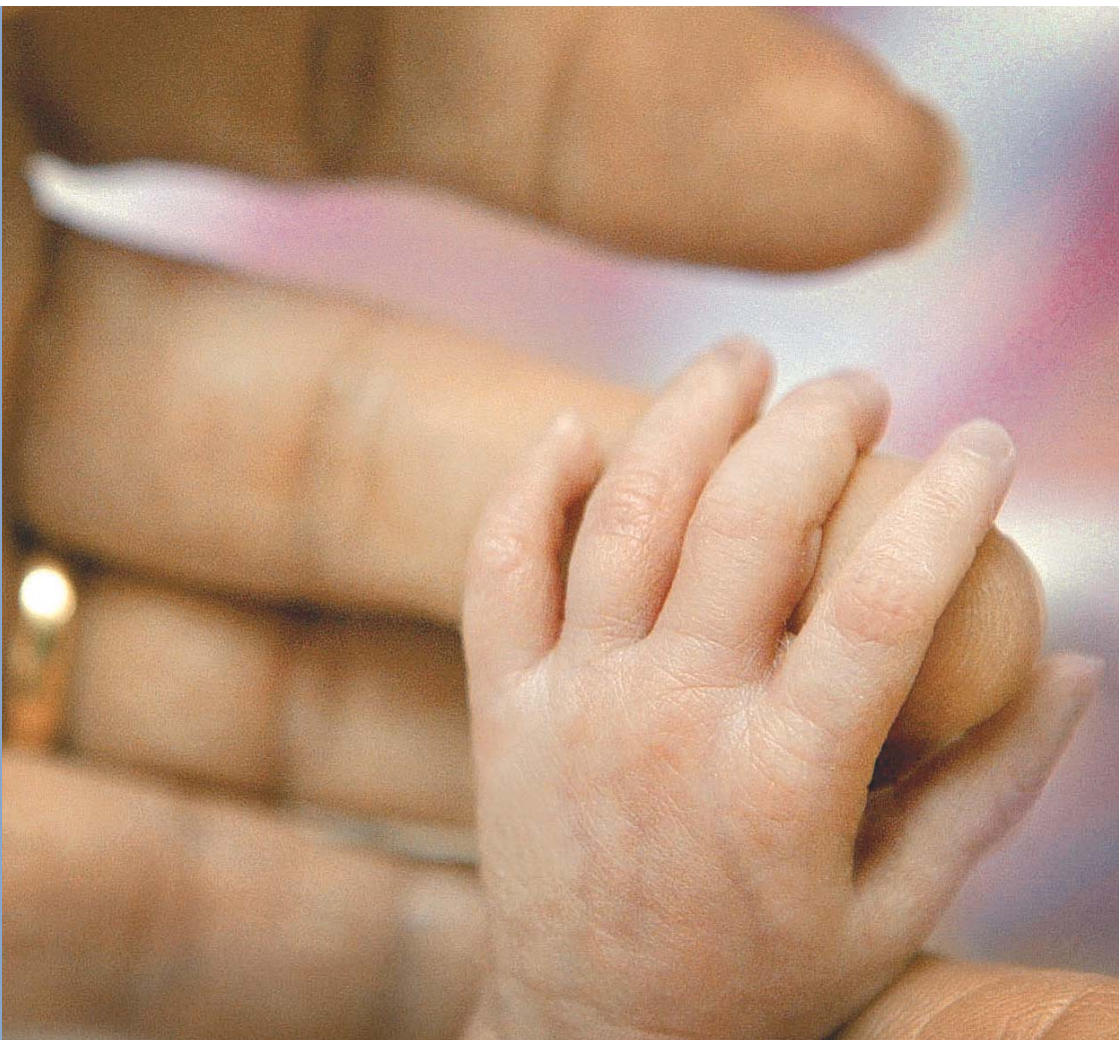


Caring for your very premature baby





Caring for your very premature baby

Acknowledgements

Caring for your very premature baby is the second in a series of booklets designed for parents of infants born before 28 weeks gestation.

This publication was made possible by the generous support and assistance of the dedicated health professionals at the Mercy Hospital for Women, the Featherweight Club and the Neonatal Advisory Group.

VicRoads and BOC Gases kindly provided car safety information.

The retinopathy of prematurity parent information is based on recommendations by the National Health and Medical Research Council of Australia (1997).

The Small Baby Project was funded by Mercy Hospital for Women and the Metropolitan Health and Aged Care Services Division of the Victorian Department of Human Services.

This booklet was written by Melinda Hall, Chad Andersen and Theresa Arnold.

Other contributors were Melissah Burnett, Tanya Darrer, Megan Galbally, Margarat Vanessen, Dagmar Voges and Bee Wong.

Contents

Research participation	1
The neonatal intensive care unit	2
First appearances	3
Common equipment	4
Caring for your baby in the NICU	5
Developmental care	7
Noise	8
Light	8
Positioning	8
Touch and kangaroo care	9
Minimal handling and clustering care	9
Baby's cues	10
Breastfeeding	11
Immunisation	12
Common problems and treatments	13
Breathing	13
Pneumothorax	14
Chronic lung disease of prematurity	14
Intravenous fluids and medicines	14
Blood transfusions	15
Infection	16
Brain haemorrhage	16

Contents continued

Patent ductus arteriosus	16
Necrotising enterocolitis	17
Eyesight	17
Hearing	18
Inguinal hernias	18
Long term outcomes	19
Levels of neonatal care	20
Transfer closer to home	21
Discharge preparation	21
Discharge criteria	22
Going home	23
Support following discharge	24
Your baby's development after discharge	25
Safe sleeping	26
Car safety	27
General car safety tips	28
Recommendations for the small baby	29
Babies with special needs	29
Postnatal depression	30
Facing the death of your baby	32
Web sites and support services	33
Reading guide	37

Research participation

Advancements in the care of premature babies have resulted from years of careful research. This research was made possible by the overwhelming support of the families of these special infants.

During your baby's hospital stay, you may be asked to enrol in one or more research projects. Participation is voluntary. Should you decide not to join any studies, neither your baby's care nor your relationship with medical and nursing staff at the hospital will be affected.

All research projects have been approved by the hospital's Research Ethics Committee to ensure the babies receive the best possible care.

The neonatal intensive care unit

The neonatal intensive care unit (NICU) is sometimes busy and confusing, with lots of activity, staff, families and visitors.

Infants are often surrounded by a great deal of 'high-tech' machinery, including a ventilator to assist with breathing, monitoring equipment, syringe pumps, and blue lights to treat jaundice. Sensors are used to monitor the baby's temperature, automatically adjusting the incubator temperature to keep the baby warm. Other sensors monitor heart rate and breathing. Blood oxygen levels are measured using a small red light taped to the baby's hand or foot.

NICU staff aim to provide infants with the best possible care to keep them safe from infection and to help them grow and develop.



First appearances

When admitted to the NICU, your baby will be looked after by a team of specialist medical and nursing staff. Your baby will be connected to a monitor, respiratory support and syringe pumps. Intravenous (IV) lines will be placed into your baby's arm or leg and perhaps into the umbilical cord.

At first glance, your baby may appear very small and frail. Because they have little body fat, premature babies are often thin and have see-through skin.

Very premature babies lose heat and moisture easily. To help maintain their temperature, these infants are nursed under a radiant heater or in an incubator with high humidity added.

Differing growth patterns, general health and genetic makeup all influence the baby's weight at birth. Table 1 provides the average birth weight of premature infants admitted to NICUs across Australia and New Zealand between the years 2000 and 2002.

Table 1

Gestation	Average birth weight	Interquartile* range
23 weeks	588 grams	532–642 grams
24 weeks	657 grams	605–721 grams
25 weeks	767 grams	685–841 grams
26 weeks	884 grams	786–971 grams
27 weeks	1,002 grams	876–1,096 grams
28 weeks	1,134 grams	994–1,256 grams

*Interquartile refers to the range between the 25th and 75th percentiles.

Common equipment

Incubator	A specialist enclosed bed used to provide a warm, protected environment for the baby
Monitor	A device for measuring heart rate, breathing rate, blood pressure, and oxygen level. There are many different types of monitors, including oximeters and trans cutaneous monitors (TCMs)
Phototherapy light	A blue light used to reduce bilirubin levels (yellow skin pigment) in a jaundiced baby
Syringe pump	A pump that delivers milk via feeding tubes in the mouth, and fluid and medications via intravenous (IV) and arterial (IA) lines
Radiant warmer	An open cot with a radiant heater overhead
Ventilator	A machine that provides assistance with breathing via a tube placed in the mouth or nose and passing into the trachea (wind pipe)
Continuous positive airway pressure (CPAP)	A machine that gives the baby oxygen/air into the nose at a low pressure to help hold open the throat and lungs and help the baby breathe

Caring for your baby in the NICU

The NICU welcomes parents, their questions and their telephone calls at any time day or night. Families are not considered visitors and are encouraged to spend unlimited time with their baby; however, you may at times be asked to limit the number of people visiting your baby. During very busy periods or when surgical procedures are being performed in the unit, parents may be asked to step out of the nursery.

To reduce the chance of infection, we ask everyone to thoroughly wash their hands as they enter the NICU and before touching their baby. People with infections should not visit until they are better. Please consult the staff if you are unwell, have a cold sore or have had a recent exposure to chickenpox, etc.

Having a preterm baby is one of the most stressful experiences a parent can have. Most parents find the NICU overwhelming and frightening.

It is common for parents to feel a range of emotions, including grief, hurt, fear, worry, anxiety, confusion and vulnerability. Feelings of sadness and depression are also common. Many grieve the loss of a normal pregnancy and lost experiences and dreams.

Delivering a very premature baby is a period of crisis for many families. The emotional 'rollercoaster' can place undue pressure on relationships between parents and other family members. Often parents struggle to deal with a sense of losing control. Support is important during this difficult time.

The doctors, nurses and social workers in the unit are very experienced and can help with comfort, information and advice. A variety of external sources of support are also available. Contact details for some of these are at the end of this booklet.

Your involvement is essential in the care of your baby. The best way to help your baby in the NICU is to be there. Learning when your baby is stressed and needs to rest and when your baby

is ready to bond with you is one of the most important things you can do for your baby, especially in the early days.

You can also determine what interaction your baby likes. By hand holding, head stroking, talking or singing, you establish a bond with your baby. The nurses will help you learn about how much and what type of contact is best.

Most babies find comfort in the gentle yet firm cupping of hands on the head and feet. You should avoid light finger touching because it can be arousing, not soothing. For some very premature babies, being touched can be stressful and staff may suggest you limit physical contact. If this is the case, it is important you still spend as much time as possible with your baby. Your baby will slowly learn to enjoy being touched.

Depending on your baby's health, a hold or kangaroo cuddle may be possible even while your baby is still being helped by a ventilator.

Although you want to make time for interacting with your baby, you should allow periods of undisturbed sleep. Let your baby set the pace for your time together.

As your baby grows and recovers, it is important you become comfortable with providing all of your baby's daily care needs.

Developmental care

A premature baby is born during an important period of their development and cared for in an environment very different from the mother's womb. Excessive noise and light, poor positioning and over-handling may have harmful effects on the infant's long term development.

Developmental care refers to a range of strategies aimed at reducing the effect of the NICU environment on the premature baby. These include minimising noise and light exposure, careful positioning, minimal handling, clustering care, positive touch and kangaroo care.

Noise

Excessive noise in the NICU is a major source of stress, which not only interrupts a baby's sleep, but can cause hearing damage. Parents can help by avoiding loud talking in the NICU, limiting visitors and closing their baby's incubator doors quietly.

Light

Bright light also interferes with a baby's sleep patterns. In the NICU, overhead lighting is kept to a minimum by using individual spotlights and natural lighting as much as possible. Cot covers made with dark material are used on incubators to shield the baby's eyes from direct light. Many units provide these covers for each baby, but parents are encouraged to make their own if they wish.

Positioning

Very premature babies benefit from being positioned in a way that promotes normal development, provides comfort, promotes sleep and reduces the chance of later neuromuscular complications. A premature baby has low muscle tone and, without support, lies in a flattened and extended position. In this position, the head falls to one side, the pelvis lies flat and the hips and shoulders rotate. This may affect their early mobility.

In the NICU, the premature baby is usually placed on their side or tummy, with support, boundaries and positioning aids, such as sheepskins, 'nests' and water pillows. Rolled towels or nappies are placed between the legs, under the hips and along the back to improve the baby's position. A sheepskin provides a soft surface for the baby to lie on. A 'nest' (rolled towel placed around the baby) provides a physical boundary the baby can nestle into and lean against, and offers a sense of security and comfort. Water pillows are used under premature babies' heads to reduce head flattening. Infants are moved regularly so they do not hold any position for too long.

Touch and kangaroo care

Touch, handling and cuddling are essential for both your baby and you as parents. We encourage this as much as possible. Touch can include holding your baby's hand, gently stroking the head and cuddling.

'Kangaroo care' is the term given to skin-to-skin holding in which a baby is placed on their parent's bare chest. Many babies enjoy this special time. Kangaroo care promotes closeness and bonding. Other proven benefits for infants include improved weight gain, decreased oxygen need and earlier breastfeeding.

Minimal handling and clustering care

Minimal handling is aimed at making sure babies have periods of uninterrupted sleep so they use less energy and grow more. NICU staff try not to wake a sleeping baby unless they really have to. Parents can do the same by waiting for their baby to wake before touching them. Sometimes it is really nice to just watch your baby sleep.

Clustered care is where tasks are performed together rather than individually at different times. This depends on each baby's sleep-wake cycles, state of alertness and medical needs. For example, if your baby has to have a blood test or an X-ray, then this may be an appropriate time to change their nappy. This will allow for longer periods of rest and 'quiet times' afterwards. Clustered care should be individualised and each baby must be watched for signs of stress.



Baby's cues

Babies respond in different ways to touch and handling. Sometimes, premature babies become stressed when handled and give signals to let us know how they are coping (see Table 2). Most babies display a range of these signs at one time or another without necessarily being stressed; however, a baby who consistently displays 'not coping' signs while being handled may need the activity modified and frequent breaks introduced.

Table 2

Baby coping	Baby not coping
alert	yawning, crying hiccups, sneezing
steady gaze	turning away, back arching
sucking	grimacing, frowning
hand to mouth movements	finger splaying
stable heart and breathing rate	change in heart or breathing rate
tolerating feeds	vomiting
smooth body movements	jitteriness
stable colour	change in skin colour

Immunisation

Immunisation against certain infectious diseases is an important part of your baby's medical care. Immunisation for the extremely premature baby usually commences at two months of age.

More information can be found in the *Understanding childhood immunisation* booklet in your baby's Child Health Record.

Common problems and treatments

The major complications very premature babies experience are the result of the baby being very immature.

Breathing

The lungs of very premature babies are small and not fully developed. Many lack an oily substance on the lung surface, called surfactant, which helps keep the lungs open. The steroid injection given to mothers before delivery helps mature the baby's lungs and stimulates surfactant production.

Some babies only need continuous positive airway pressure (CPAP) to help keep their lungs and throat open. While on CPAP, oxygen/air is delivered under a low pressure through the baby's nose, allowing the baby to do all the breathing. However, many premature babies can't breathe adequately by themselves and need support from a ventilator.

Using a ventilator requires a small tube to be passed through the baby's mouth into the trachea. The ventilator then blows small, frequent puffs of oxygen/air into the lungs. Most babies still do a lot of breathing themselves, even while ventilated. When the baby's lungs are better, the ventilator pressures and rate are weaned. The baby is then taken off the ventilator and treated with CPAP before needing no help at all.

You will notice the doctors and nurses will often adjust the ventilator and oxygen level to make sure the baby's oxygen and carbon dioxide levels are normal and to keep the baby's lungs in the best condition. X-rays are used to examine the lungs and make sure the breathing tube is in the correct position. This is all part of the normal day-to-day care of the premature baby.

Pneumothorax

About 10 per cent of babies who need help from a ventilator develop a small hole in their lung. The hole, also referred to as an air leak or pneumothorax, allows air to escape under the chest wall, thus compressing the lung. Treatment involves draining the air leak by placing a small tube through the chest wall for a few days. Infants with a chest tube are given pain relief and sedation for comfort during this time.

Chronic lung disease of prematurity

Ventilators can be life-saving in very small babies, but unfortunately, they can also damage the lungs. There is often a balance between keeping babies on the ventilator to help them with breathing and getting them off the ventilator completely. Sometimes this is not easy.

Many of the smallest babies develop a condition called chronic lung disease of prematurity (CLD). This is caused by a combination of factors, including infection of the placenta before birth, ventilators, oxygen and infection after birth. These infants usually need prolonged treatment with oxygen while their lungs slowly heal. Some will be discharged home while still being treated with oxygen.

Many of these babies have trouble with viral lung infections in the first year following discharge and need to be admitted to hospital. Despite this, they are likely to be able to run around the playground with other children by the time they are ready for school.

Intravenous fluids and medicines

Umbilical lines

In many small babies, special lines are placed into the umbilical cord blood vessels. (These vessels connected the baby to the placenta while in the womb.) This does not hurt the baby.

Often two umbilical lines are used. A venous line is used to give the baby nutrition, such as sugar, protein, fat, salt and water. An arterial line is used to continuously measure the baby's blood pressure and take blood samples.

Intravenous lines ('drips')

An intravenous (IV) line is used soon after birth if the umbilical vein cannot be used. Later, IV lines are also used to give the baby fluids, antibiotics or a blood transfusion. IV lines are often replaced every day or two because they have become blocked or are leaking, or to reduce the chance of infection.

Long lines

After about a week, the umbilical lines are removed and the belly button heals over to be normal. Subsequently, many of these babies have 'long lines' inserted. These are long, narrow IV lines that can stay in the veins for a couple of weeks. They are used for intravenous nutrition until the baby is tolerating milk feeds.

Blood transfusions

Blood travels around the body taking oxygen and food to the cells and carrying away waste. Blood contains several components, including red blood cells, platelets and plasma (the liquid).

Red blood cells contain haemoglobin, which carries oxygen. Very premature infants become anaemic (a lack of red blood cells) as a result of blood sampling and immature production of red blood cells, and need a transfusion. Transfusions of red blood cells are referred to as 'blood transfusions' or 'top-ups', and more than 90 per cent of infants born weighing less than 1,000 grams require them. On average, these infants require four or five transfusions during their hospital stay.

Platelets are blood cells that help the blood clot. Some infants have a low level of platelets at birth.

Severe infections and poor production by the bone marrow also lead to a low platelet count. These infants may require platelet transfusion to prevent or control bleeding.

Very premature babies commonly have low levels of other blood clotting factors. If these factors are too low, the baby may be given substances called fresh frozen plasma (FFP) or 'Cryo' through a drip.

Before the transfusion, the baby's blood is checked for blood type and cross-checked against the mother's blood. The transfusion is given through a drip into the baby's vein. Depending on the blood product and reason for its use, a transfusion can take anywhere from minutes to several hours.

All blood components are produced from donated blood. The Australian Red Cross Blood Service carefully screens the donors, cross-matches the blood for each individual, and manages the supply and distribution.

As with all medical procedures, blood transfusions involve some risks. These are limited as much as possible by the care taken when the blood is collected and by ensuring that blood is only given when appropriate.

The risk of viral infection is extremely low; for example, the risk of contracting HIV is less than one in 7,000,000.

Infection

Premature babies are prone to infection. Because of this, very premature babies are nursed in an incubator and anyone who touches the baby must clean their hands very carefully by washing them or using alcohol hand rub.

If a baby develops an infection, they are often pale and quiet, don't tolerate milk feeds and sometimes need more oxygen and help from the ventilator. If infection is suspected, blood and other fluids are tested for infection and antibiotics are started immediately. The infant usually starts to recover within 48 hours.

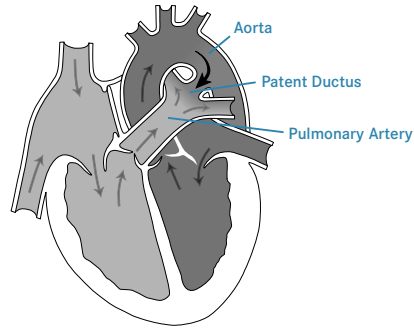
Brain haemorrhage

The brain of a premature infant is very fragile and can be affected by events before, during and after delivery. While the baby is in the NICU, a number of routine head and brain scans will be performed. These scans look at the structure of the brain and for any bleeding or bruising. Head ultrasounds are helpful in predicting the baby's long term outcome.

Some babies develop a bleed or intraventricular haemorrhage (IVH) in or around the brain. Most of these are not serious; however, occasionally these can be large and potentially cause problems with later development.

Patent ductus arteriosus

The ductus arteriosus (DA) is a normal blood vessel above the heart. When the baby is still in the womb, the DA directs blood from the placenta, past the lungs to the body.



Normally, when the baby is born at term, the ductus closes by itself within 24 hours of birth. In premature babies, the ductus often remains open or 'patent', hence the term patent ductus arteriosus (PDA). Instead of redirecting blood away from the lungs, the ductus allows blood to overfill the lungs, making them heavy and 'water logged'. When this happens the baby is often unstable and needs more help from the ventilator.

At this time, the baby will have an ultrasound or echocardiogram to look at the structure of the heart and the direction of blood flowing through the ductus. If the ductus arteriosus is causing a problem, the baby will be given some medicine called Indomethacin.

Indomethacin is similar to aspirin and works to close off the ductus. In the majority of babies, this is all that is needed to close the PDA; however, some of the smallest babies have ongoing problems with an open ductus despite receiving Indomethacin. A cardiologist (heart specialist) will review these babies. Sometimes the cardiologist will recommend an operation to close the ductus.

Necrotising enterocolitis

Necrotising enterocolitis (NEC) is an infection of the bowel wall. Babies who develop this infection can become rapidly ill. Babies with NEC are treated with antibiotics. Milk feeds are stopped to allow the bowel to rest.

Babies with NEC often require more support with breathing and to maintain their blood pressure. Many will also need transfusion of blood and platelets (clotting cells).

Some need to have an operation. If this is necessary, the baby may be transferred to another hospital.

Eyesight

Very small babies are at risk of developing an eye condition called retinopathy of prematurity (ROP). ROP affects the developing blood vessels of the retina, at the back of the eye.

The main cause of ROP is prematurity, so the more prematurely the baby is born, the greater the risk of ROP. Oxygen treatment and the baby's condition may also influence whether ROP develops or becomes severe; however, some very premature babies who have no serious illnesses still develop the condition, while others who have been very ill do not.

The ophthalmologist will examine all babies of birth weight less than 1,250 grams at intervals. The first examination is usually between 30 and 32 weeks gestation. The purpose of the ophthalmologist's examinations is to diagnose babies who are developing severe ROP, so they can be treated early. If your baby is diagnosed as developing severe ROP, it will be discussed with you.

ROP is very common and in most babies it is mild, settling completely without treatment and therefore not affecting the baby's vision. For those few babies who require treatment, it is usually successful.

Sometimes an eye examination is necessary after you take your baby home. This will be arranged prior to discharge. It is very important you keep this appointment.

Hearing

Hearing problems are more common in sick and very premature babies. As such, all infants in this hospital have a hearing screening test just before discharge. This is a simple, pain-free procedure performed by specialist staff in the nursery.

Some of the smallest babies do not 'pass' their first hearing screen because they may have fluid in their middle ear as a result of having had feeding and/or breathing tubes through their nose.

This will often disappear. These infants will receive a more detailed hearing test following discharge.

Inguinal hernias

Inguinal hernias present as a lump or bulge in the groin or scrotum and develop because of a weakness in the muscles of the abdomen. The swelling often gets bigger when the baby cries and may get smaller or go away when the baby relaxes.

The incidence of inguinal hernia in premature infants weighing less than 1,000 grams at birth is around 30 per cent. Hernias are more common in male infants and those who have a history of prolonged breathing support. They are usually painless, but may cause discomfort, fussiness, or even bowel obstruction. Surgical repair is often recommended before the baby goes home.

Long term outcomes

The long term effects of early birth can be difficult to predict in premature babies. Some very premature babies are slow to reach early milestones, such as rolling, sitting and crawling, although this does not necessarily indicate a long term problem.

Mostly, paediatricians follow up premature babies to make sure they are growing and developing normally. Some of these babies will be referred to other health professionals, such as physiotherapists and speech therapists. It is likely premature babies will have many appointments with paediatric specialists in the first few years.

Mild disability is relatively common in infants who are born very prematurely. Infants with mild disability are likely to be independent, although they may need some extra support through their preschool years. They may have minor difficulties with coordination, learning, speech and sometimes problems with vision, such as a squint in one eye.

Few very premature infants have major disabilities. Those who do can have several problems, such as difficulty with feeding, walking, hearing, language development and vision. Overall, the majority of premature babies do well.

Levels of neonatal care

In Victoria, neonatal care is classified into three levels according to facilities offered, with each level having admission criteria based on age, weight, general health and feeding method.

Victoria has four Level III units, commonly referred to as NICUs, which care for infants not only from across the state, but also Tasmania and the border regions of South Australia and New South Wales. These units provide sick and premature newborns with specialised treatment, including respiratory support (assistance with breathing). Some also offer surgery to the infant with complex medical needs.

Victoria also has many local and regional hospitals with Level II special care nursery (SCN) facilities. Generally, premature infants born after 32 weeks are cared for in Level II units. Level II units provide infants with IV fluids and medications, oxygen therapy and monitoring of heart rate and breathing. Infants are also admitted for continuing care following a NICU stay.

Level I units provide care for healthy babies requiring short term observation following delivery.

Transfer closer to home

Having a very premature baby places enormous pressure on families, especially those living a long distance away from the NICU.

Work and family commitments combined with frequent travel to the NICU is exhausting for parents. To ease the pressure on families and to make beds available for other infants in need, we transfer babies to a hospital closer to home as soon as possible. Infants are transferred by road or air ambulance and will be accompanied during the trip by specialist nursing or paramedical personnel.

As the time for the move nearer home approaches, parents are encouraged to visit the receiving hospital to familiarise themselves with the special care nursery.

Discharge preparation

Some infants, especially those living locally, may be discharged home directly from the Level III NICU.

Throughout your baby's hospital stay, you will have become familiar with and participated in your baby's care. As discharge approaches, you will be further supported in caring for any special needs your baby may have. Cardio-pulmonary resuscitation (CPR), home oxygen therapy, and administration of medications are commonly taught to parents taking their premature baby home.

Prior to discharge, you are encouraged to stay overnight in the parent accommodation rooms. 'Rooming-in' provides an opportunity to become confident and competent in the care of your baby. During your stay, nursing and medical staff will support you as feeding and settling patterns are established and you learn how to manage your baby's needs.



Discharge criteria

Your baby's general health and wellbeing will be the guide as to when your baby will be discharged. To be safely cared for at home, your baby must be:

Medically stable, with no apnoeas (pauses in breathing) or bradycardias (slowing heart rate)
--

Able to maintain body temperature in an open cot
--

Gaining weight at a steady rate

Feeding well (sucking all feeds from the breast, bottle or cup)

Many very premature infants meet these criteria and are discharged home around the time of their 'due date'.

Your baby will not be discharged home until you and the medical and nursing staff are satisfied your baby is ready.

Going home

Taking your precious baby home is a time for celebration, but it can also be a time of uncertainty as you finally accept full responsibility for your baby. It is perfectly normal for parents to express a mixture of emotions, including relief, fear, happiness and apprehension.

A follow-up appointment will be scheduled for several weeks after discharge. At this time, medical staff will assess your infant's health, growth and development. This review, along with any other medical appointments your infant may require, will be arranged prior to hospital discharge.

For the baby with particularly challenging medical needs, the first year of life may be consumed by medical appointments, physiotherapy, speech therapy, and so on. For some, this is the reality of being born before their time.

To ease your baby's transition into the community, it is recommended you introduce him or her to your family doctor shortly after discharge.

Support following discharge

In the weeks following discharge, experienced nursing staff will visit you at home. The frequency of visitation generally depends on your infant's progress and any special needs, for example, home oxygen therapy.

Home visitation is a service offered to bridge the transition from hospital to home. The main focus of this service is to ensure your baby is feeding well and gaining weight. You can discuss breastfeeding concerns and other general health issues for you and your baby with the visiting nurse.

Most home visitation services also provide a link to the maternal and child health nurse in your local area.

For non-urgent concerns, parents should contact the discharging neonatal unit, the home visitation nurse or their maternal and child health nurse.

For emergency assistance, please call for an ambulance on **000**.

Your baby's development after discharge

Most very premature babies develop normally; however, one needs to take into account their prematurity. If your baby is nine months old but was born three months early, their size and development will be around that of a six-month old baby.

Some babies who were born very prematurely may be slower in achieving their developmental milestones. Babies who are developing slowly may arch their head and back and sometimes stiffen their legs, feel floppy around the body or find it difficult to hold up their head, experience feeding difficulties or be unsettled.

Of course, all babies may experience these difficulties at one time or another. Usually these problems persist for a short period and there is no need for concern; however, for some babies who were born prematurely these characteristics can indicate a problem with development.

If you're concerned about your baby's development at any stage, speak to your doctor. A paediatric physiotherapist can also give you ideas for play and activities at home to promote development.

Safe sleeping

Research shows that premature infants have a small increase in risk of dying from Sudden Infant Death Syndrome (SIDS). The actual cause of SIDS is unknown, however there are simple ways parents can reduce the risks to their infant:

Put your baby on their back to sleep.
(This position will be encouraged before discharge, once your baby is stable.)

Ensure your baby's face remains uncovered while sleeping.

Keep toys, quilts, doonas, pillows and cot bumpers out of the cot.

Ensure your baby does not overheat.

Use a firm, clean mattress.

Use a cot that meets the Australian Safety Standards.

Keep your baby smoke-free.

Cigarette smoke is harmful to babies before and after birth.



Car safety

The car safety message is not new for most parents, however many are unfamiliar with the special needs of the premature infant. As discharge draws near, parents are encouraged to give thought to protecting their infant while travelling.

In Victoria, all infants must be secured in an approved restraint that is properly fitted to the vehicle and adjusted to correctly fit the infant's body. Infants less than 9 kilograms are required to be transported in rear-facing restraints that support the neck and back in the event of an accident. Small infants are usually safest in an infant capsule fitted with a harness. Capsules provide a more reclined position, while supporting the neck and head in the event of a sudden stop. Many convertible-style car seats are too big for premature infants.

Restraint placement and fitting

Rear-facing child restraints must not be placed in vehicle seats that face rearward or sideways, or positioned adjacent to an airbag which may be activated in the event of an accident. For further advice, consult the vehicle owner's manual.

Parents are advised to have the infant's restraint installed and checked before taking their baby home. Restraint fitting stations, a joint initiative of the RACV and VicRoads, are located throughout Victoria to help people correctly install their child restraints.

General car safety tips

✓	Back seat travel is safest.
✓	The harness must always fit as snugly as possible. Adjustments to the harness will need to be made frequently as the baby grows.
✓	The shoulder straps should come from slots that are level with or just above the baby's shoulders.
✓	Ensure loose items are locked in the boot or glove box or secured behind a cargo barrier in station wagons. Loose items can be projected causing injuries or death if the car moves or stops suddenly.
✗	Do not wrap your baby in a bunny rug or blanket prior to placing them in the car restraint because the harness will not fit correctly and your baby may overheat. Instead, place the blanket over your baby once secured.
✗	The baby must not wear thickly folded or double nappies while secured in a child restraint because this leads to uneven back support and potential spinal damage in the event of an accident.

Recommendations for the small baby

The following recommendations for the safe transportation of premature and low birth weight infants have been adapted from the American Academy of Pediatrics (AAP) Committee on Injury and Poison Prevention (1996):

Car seats should only be used for travel.

Never leave an infant unattended in a car seat.

If using a convertible style car seat, it is important to recline the seat to the maximum tilt position so your baby's head does not hang forward. Ideally the seat should tilt half-way back, at about a 45 degree angle (refer to the manufacturer's label).

Small babies may benefit from being supported during car travel. The space around your baby may be padded with rolled-up bunny rugs or towels. Place them beside your baby's head and along the sides of the seat, ensuring that they cannot fall over the face. **It is important, however, that you do not put any padding under your baby: the head, buttocks and back should be flat against the back of the car seat.**

Babies with special needs

Many infants born prematurely have difficulties holding their head upright, especially while travelling in a car restraint. Oxygen levels tend to fall when an infant's chin is resting near his chest. If this is the case for your baby, an adult should travel in the back seat to watch your baby's breathing.

Some babies are discharged home with apnoea monitors, portable oxygen tanks or other special equipment. Ideally, oxygen cylinders should be transported in the backpack provided and be secured in the lap-sash seatbelt of the backseat.

Postnatal depression

Postnatal depression (PND) affects one in seven women giving birth in Australia. PND usually occurs within the first 12 months of having a baby, often within the first few weeks or months. Mothers who have delivered prematurely are even more likely to be touched by PND.

The causes of PND are unknown; however, the enormous physical, emotional and social changes involved in becoming a parent of a premature baby play a significant role.

Symptoms of PND are varied and may include a combination of the following:

irritability and tearfulness
sleeping problems
anxiety and panic attacks
loss of appetite
feelings of being unable to cope
negative thoughts, including feelings of guilt
difficulties in remembering or concentrating on things

A woman with PND may withdraw from everyone, including her baby and partner. This is a symptom of the disorder and does not reflect on her abilities to be a 'good' mother. Once the depression lifts, the mother will be able to once again feel her full range of emotions and start to enjoy and bond with her baby. In the meantime, she might need some extra help from family and friends.

Support and patience from family and friends is perhaps the most crucial factor in a woman's recovery. Talking about her feelings to a professional counsellor or with other women in support groups can be helpful. In more severe cases, antidepressants and other medications might be used to bring about a change in mood.

Professional support and treatment are readily available through a number of services, including the mother's general practitioner or family doctor, mother/baby clinics, and maternal and child health nurses. NICU staff are also able to provide a link to appropriate support personnel. Parents are encouraged to seek help at any time throughout their baby's hospital stay.

Left untreated, PND can have harmful effects on the mother and her relationships with the baby and other family members; however, with appropriate treatment, women with PND will recover in time.

Facing the death of your baby

Many parents facing the prospect of losing their baby experience feelings of sadness, shock, anger and sometimes confusion. These feelings are often compounded by the need to make decisions about the ongoing care of their baby. If further treatment cannot help your baby survive without serious disabilities, you will be asked your opinions about stopping treatment. In most cases, this decision need not be rushed. It is important for parents and doctors to make the decision that is right for the baby and the family. It can be valuable for parents to discuss the withdrawal of life support with their family and close friends.

Some parents may wish to have their baby blessed or baptised, especially when faced with the decision to withdraw treatment. This can be performed by the parents, a friend or close family member, nursing staff, hospital chaplain or a celebrant of the family's faith.

Usually when a loved one dies, there are many memories of time spent together, which serve as a comfort to those who grieve them; however, in the case of a preterm baby, these memories will be limited to the NICU. While treatment is being withdrawn, and after the baby has died, parents and family are given the opportunity to spend time with the baby.

During this time, many parents choose to hold and comfort their baby. Some also choose to bathe and dress them. Everlasting memories can be made by taking photos or video and making ink or clay prints of the baby's tiny hands and feet.



Web sites and support services

Austin Health – Professorial Unit (Mother/Baby Unit)

Banksia House, Repatriation Campus
Banksia Street, Heidelberg 3084

Telephone: (03) 9496 2199

Austprem

Providing friendship, information
and support to parents and carers of
prematurely born babies and children

www.austprem.org.au

Australian Breastfeeding Association

Telephone: (03) 9885 0855

www.breastfeeding.asn.au

Australian Multiple Birth Association

www.amba.org.au

Bonnie Babes Foundation

Grief counselling for the loss of a baby
through miscarriage or stillbirth, or
following death in the neonatal period

Telephone: (03) 9758 2800

www.bbf.org.au

Featherweight Club

Providing support and information
for premature babies and their parents

www.featherweightclub.com

Immunise Australia

Immunisation Infoline: 1800 671 811

www.immunise.health.gov.au

Maternal and Child Health Line

Telephone: 13 2229 (24 hours)

Mercy Hospital for Women Ante/Post Natal Depression Clinic (Mother/Baby Clinic)

Providing counselling, referral and treatment on an outpatient basis to women who are suffering antenatal and/or postnatal depression and related disorders

Telephone: (03) 8458 4444

Mercy Hospital for Women Breastfeeding Support Centre

Telephone: (03) 8458 4444

Post and Ante Natal Depression Association (PaNDa)

Telephone: (03) 9428 4600

Preterm Infants' Parents' Association (PIPA)

www.pipa.org.au

RACV (child restraint information)

Telephone: (03) 9790 2190

Royal Children's Hospital Child Safety Centre

Telephone: (03) 9345 5085

www.rch.org.au/safetycentre

Royal Women's Hospital Breastfeeding Education and Support Service

Telephone: (03) 9347 3024

SANDS (Victoria)

24-hour support for bereaved parents, families and friends following the death of a baby through miscarriage, stillbirth or shortly after birth

Telephone: (03) 9899 0218

www.sandsvic.org.au

SIDS and KIDS Victoria

24-hour crisis and ongoing bereavement support

Telephone: (03) 9822 9611

Freecall: 1800 240 400
(from most landlines)

www.sidsaustralia.org.au

Monash Medical Centre Mother Baby Unit

246 Clayton Road, Clayton 3168

Telephone: (03) 9594 1414

Translating and Interpreting Service

24-hour service

Telephone service:
13 1450

On-site service bookings:
1300 655 082

Victorian Infant Collaborative Study (VICS)

Dedicated to providing support and information to the parents and families of premature babies

www.vics-infantstudy.org.au

Werribee Mercy Hospital Mother Baby Unit

Inpatient unit providing a bed-based service for women with postnatal depression and related disorders

300 Princes Highway, Werribee 3030

Telephone: (03) 9216 8465

Victorian hospitals with NICU facilities

Mercy Hospital for Women

163 Studley Road, Heidelberg 3084

Telephone: (03) 8458 4444

Monash Medical Centre

246 Clayton Road, Clayton 3168

Telephone: (03) 9594 6666

Royal Children's Hospital

Flemington Road, Parkville 3052

Telephone: (03) 9345 5522

Royal Women's Hospital

132 Grattan Street, Carlton 3053

Telephone: (03) 9344 2000

Reading guide

Care around preterm birth: A guide for parents by the National Health and Medical Research Council (1997) can be downloaded directly at

www.nhmrc.gov.au/publications/synopses/cp52syn.htm

Further reading material is usually available on request from the hospital's Neonatal Unit or Social Work Department.

The Bonnie Babes Foundation has a free publication, *You are part of our lives and will always live in our hearts*. This book contains information that can help families cope in their time of grief. Many hospitals have copies of this book. If yours does not, please contact the Foundation on (03) 9758 2800 and a copy will be mailed to you.

Diagram on page 18 from MediClip image copyright 2005 Lippincott Williams & Wilkins. All rights reserved.

